



Multiple Sclerosis Society

Registered Charity  
1139257

# Shrewsbury & District Branch

Issue 68

Jul / Aug  
2014

*Welcome to your SUMMER Newsletter:  
As mentioned in the previous edition, we  
will now be publishing on a quarterly basis.  
In future, publication dates will be October,  
January, April & July. Any items for inclusion  
should be with me by the 10<sup>th</sup> day of these months.  
Many thanks. Mím.*

Help needed on our  
**BIG town centre TIN  
COLLECTION** - please  
see Pg 2.

## Branch Helpline

Any of you who have tried to call the branch helpline recently will have encountered problems. The phone may have given an 'engaged' tone, or invited you to leave a message – but in fact the line has been out of operation for about 8 weeks. The problem was finally resolved on 26<sup>th</sup> July – following numerous calls to BT and even more promises that they were fixing it. So if you did ring in the last few weeks, and left a message I'm afraid that we probably didn't get it, so please ring again. We are sorry for any inconvenience caused.



## Campaign news



A new MS pill called **Tecfidera** (also known as *dimethyl fumarate*) has received the final stamp of approval from NICE and the SMC. Pending an appeal period, it should be freely available on the NHS to people with active **relapsing remitting MS** by autumn. However, NICE has not recommended the treatment for those with highly active or rapidly evolving relapsing remitting MS (for whom other treatments are available such as Lemtrada, Tysabri and Gilenya).

The pill is taken twice a day and is proven to cut relapse rates and may also delay disability progression. It is considered to be more effective in reducing relapse rates, and as effective for disability progression as existing beta-interferon treatments.

Nick Fijke, Director for Policy & Research at the MS Society says: "We're delighted that NICE has finally approved Tecfidera after their initial negative review of the drug earlier this year. It's the third new drug to be approved for people with relapsing remitting MS over a number of months, so today marks a significant step forward in the treatment of the condition.

**If you have MS you have the right to request an appointment with your neurologist to discuss your treatment options.**

**Find out more on the MS Society website. [www.mssociety.org.uk](http://www.mssociety.org.uk)**

# MS SHREWSBURY SUPPORT GROUP

## HAMAR CENTRE PROGRAMME 2014

On the first Thursday of each month people with MS can meet at the **Hamar Centre** for support and information, and to have the opportunity to do beneficial exercise. Please note: you **DO NOT** need to be a member of the MS Society to come along.

There is also a speaker in the afternoon – topics are varied and interesting. A care assistant is available all day to help with your personal needs.

The day starts at 10.00 with an exercise session from 10.30 to 11.30. You can bring a packed lunch, or sandwiches can be purchased from the hospital canteen. Tea and coffee is available all day. Lunch is followed by a speaker at 1.00. There is usually time for a drink and a chat before going home. If you have any queries or questions please call the **Branch Helpline 01743 718641**. We would love to see some new faces !

### Forthcoming Speakers

- |                                  |  |
|----------------------------------|--|
| <b>7<sup>th</sup> August.</b>    | <b>John Butterworth "Local Hotel with Famous Guest List"</b> |
| <b>4<sup>th</sup> September.</b> | <b>Lee Lewis "Royal Voluntary Service"</b>                   |
| <b>2<sup>nd</sup> October.</b>   | <b>West Shropshire Talking Newspaper for the Blind</b>       |
| <b>6<sup>th</sup> November.</b>  | <b>Pam Clarke "Holiday Experiences"</b>                      |

**Tin Collections – Update** We had a very successful day in Bridgnorth. Our thanks go to Stephanie Ball, and Karen & Paul Richards who joined Jock & I on a hot sunny day in Bridgnorth. Total raised was **£433.22**.

**We have one more tin collection planned for this summer:**

**SHREWSBURY TOWN CENTRE – Saturday 16<sup>th</sup> August.**  
**This is our biggest collection of the year and we need lots of collectors.**

**WE DESPERATELY NEED COLLECTORS FOR THIS, PLEASE LET US KNOW IF YOU CAN HELP, OR IF YOU HAVE ANY FAMILY OR FRIENDS WHO COULD HELP US!** If you can help please contact Joy on 01743 352622

**As mentioned in the last Newsletter, our tin collections are really worthwhile. In 5 years we have raised over £20,000!!! Our recent collection at Bridgnorth, which only involved 5 collectors, raised over £400!!**



**HELP**



## Shrewsbury & District MS Society Annual Meeting



**The Annual Meeting and Summer Lunch** was held on Saturday 28<sup>th</sup> June 2014, at The Lord Hill Hotel. There were 15 members present, together with 8 supporters / carers.

The Chairman introduced the committee members and thanked them for their support throughout the year. The Treasurer explained the financial figures, in particular, the large contribution made by Mrs Margaret Owen's "Snowdrops and Hellebores" day at The Patch. He thanked also the considerable numbers of supporters who have helped with the various collections throughout the year.

The Committee Members, having indicated their readiness to stand again, were voted in en-bloc for the next year.

The Treasurer reported that the committee had been approached about purchasing replacement / new equipment for the Neuro Physio Department at RSH. A number of members indicated their use of the Standing Frame which is one of the items being considered. There was general support for the committee to purchase such items. This will be discussed in conjunction with Sandy Ramsay, Clinical Lead Physio, Neuro Outpatients. A further update on this matter will be reported in a future newsletter.

The next function for members to attend will be the Christmas Lunch and details will be given in the next newsletter.

**David Robbins**

### Pedal for health taster sessions

**1:00pm - 3:00pm**

**Shrewsbury Sports Village, Sundorne Road, SY1 4RQ**

Travel  
Shropshire  
.co.uk

Looking to get back on your bike or just getting started? Why not join one of these free taster days? All abilities welcome!

**Dates in 2014:** 17 September 22 October 29 October 26 November

**Try a bike** Try one of our adult, child, tandem or adapted cycles or bring your own bike and have a ride on the cycle track. Gain help with your riding skills and learn about cycling opportunities to improve your confidence.

**Rideabouts** Let us take you on a short, gently paced cycle ride around the Sports Village and onto the local cycle path. Bring your own bike or use one of ours (available on a first come, first served basis)

**Cycle surgery** Talk with our advisers about cycling, what bike and accessories to buy, suitable cycle routes and other ride opportunities. Plus bring your bicycle for a free safety check or advice on adjusting it or fixing issues.

**For more info call 01743 253008 or email**  
[cycle.shrewsbury@shropshire.gov.uk](mailto:cycle.shrewsbury@shropshire.gov.uk).

Shropshire  
Council

# LIVING WITH MS – FLINTSHIRE

On Saturday 21<sup>st</sup> June, Gill and I, together with new member Chris George, attended a 1-day event held by MS Cymru in Ewloe, Flintshire (near Hawarden). Besides an invitation to all branches in North and Mid-Wales, it seems that some members of Shrewsbury & District branch were also sent an invitation. Fortunately, Gill was one of the lucky ones.

After a couple of short sessions reporting back on the work of MS Cymru during 2013, the day was then given over to specific MS matters. The first related to the MS Society's commitment to support and inform the estimated 75,000 families and carers who support a relative or friend with MS. The aim is to link the 300 local MS branches with local carers' projects to enable a greater level of support / information within each area. With Carers Week 2015 in mind, I shall be looking into what support organisations there are locally and regionally that the branch can tap into. In the meantime, I have several copies of a booklet for relatives and friends supporting someone with MS. If anyone would like a copy, please see the information below.

The other major morning session was reporting the MS Society's research programme. After an initial explanation of the causes of MS, the speaker went on to explain the new advances in research for both remitting and relapsing, and progressive sufferers. There is considerable collaboration with many organisations across the UK and internationally, working on the top 10 research priorities, which are:-

1. Which treatments are effective to SLOW, STOP or REVERSE the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for FATIGUE in people with MS?
4. How can people with MS be best supported to SELF MANAGE their condition?
5. Does early treatment with AGGRESSIVE DISEASE MODIFYING DRUGS improve the prognosis for people with MS?
6. Are VITAMIN D supplements an effective disease modifying treatment for MS?
7. Which treatments are effective to improve MOBILITY in people with MS?
8. Which treatments are effective to improve COGNITION in people with MS?
9. Which treatments are effective for PAIN in people with MS?
10. Is PHYSIOTHERAPY effective in reducing disability in people with MS?

**There are active Working Groups set up to investigate No's 3, 5 and 6.**

The rest of the day was given over to 4 different sessions, so everyone could choose two each:-

- **Getting to Grips with PIP (Personal Independent Payment).**
- **Fatigue Management and Exercise.**
- **Family and Carers' Support and Information.**
- **Access to Disease Modifying Drugs.**

Gill wanted to attend the second and fourth, so I attended the first and third.

**The following are our thoughts from each session.**

There is so much that could be covered about **PIP** and the changeover from **Disability Living Allowance**, it is impossible to condense it here. If you are between the ages of 16 and the State Retirement Age (currently 65) then you will be assessed for PIP. Here are some TOP TIPS offered:-

- When making a claim, DO IT by LETTER and send it through the POST. DON'T DO IT over the phone.
- DON'T give the Department for Work and Pensions your home phone number.
- ALWAYS get advice when filling in the form.
- KEEP A COPY of everything you provide and send.
- DON'T be afraid to appeal – most full appeals are successful.
- ONLY ask for a home visit if you have difficulty leaving home.

The MS Society has produced a new booklet about claiming PIP, which includes the criteria for assessment and the scoring process. Having got a copy, it has been passed to Harold Toone. I shall be applying for more copies so they can be given to those who will need them.

The session on **Carers** was reporting firstly on what had been achieved by MS Cymru in North Wales during 2013. The Carers Week 2014 had been a partnership with a number of similar organisations: The objectives for the week had been:-

- Raising the profile of the role of caring and encouraging local groups to organise events and activities.
- Helping the public identify themselves as carers and to be able to access support, advice and information.
- Highlighting the challenges of caring and campaigning for funding.

With 71% of people with MS indicating they receive care and support from partners, family and friends, that means nearly 1 in 8 in the population will take on a caring role. I am aiming to contact 'Carers.org' to investigate what local or regional services exist to see what the branch can offer in the way of help.

The **Fatigue Management and Exercise** session looked at identifying fatigue (you may be suffering but not realise), and how to take charge of your situation.

Definition of Fatigue. MS Council for Clinical Practice Guidelines 1998

***"A subjective lack of physical and / or mental energy that is perceived by the individual or care-givers to interfere with usual and desired activities".***

OR

***"Fatigue feels like being weighed down, as if you are trying to walk up to your neck in deep, muddy water in heavy, wet clothes carrying shopping bags full of rocks".***

Those taking part in the session described what they felt caused their fatigue, – heat, lack of sleep, medication, stress, exertion, and how it made them feel. Fatigue is not just feeling tired, it also covers mood swings, lack of interest, inability to concentrate. The list covers many symptoms.

Having agreed that, at some time, we all suffered with fatigue (we just did not realise that was what the problem was) we then heard about techniques to help manage the condition.

Exercise can play an important part in taking control of fatigue. The MS Society has a leaflet giving advice on **Fatigue (ES14)**, and **Exercise and Physiotherapy (ES21)**.

Another part of managing fatigue is:

- Planning
- Pacing
- Prioritising
- Delegating
- Positive mental attitude

The session on **Access to Disease Modifying Drugs** covered many drugs suitable for Relapsing and Remitting MS. It talking about development of drugs, and we were told that, from when a proposal for research was raised, until the final drug was available for use by sufferers, could take up to 17 years. Funding, as always, was the key. Not all drugs used at the present time are available in England and Wales, Scotland having its own programme. The campaign "Treat Me Right" highlights the difficulties in getting access to DMDs.

We hope you find this information helpful. It has got us thinking about a similar event in our area.

**David & Gill Robbins**

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## **For Sale: Quingo Sport Mobility Scooter**

The Quingo Sport is intended for occasional indoor use and for outdoor pavement use and rougher surfaces at 4mph. It is also capable of road use† at up to 8mph. It is ideal for short/medium/longer journeys, visiting friends, shops, shopping centres or just out and about. It can also be transported in most standard estate sized cars.



2 years old – very low mileage. Silver with black seat, headlights, indicators and basket.

Cost £5000, **asking price £3500. Please contact Sheila Graham on 01743 241063 for further details.** (Picture & some of this information taken from brochure – actual item for sale may differ slightly)



# Yeoman Singers

Another wonderful concert was held at St Alkmund's Church by the Yeoman Singers, in aid of our local branch. The choir performed Henry Purcell's 'Come ye Sons of Art' – a cantata first performed for the 33<sup>rd</sup> birthday of Queen Mary in 1694.



This concert raised £300 – which brings the total raised between the last two concerts to £728 !! Our thanks go to the Yeoman Singers for their hard work and wonderful entertainment.



## Shrewsbury Trefoil Guild.

On June 4<sup>th</sup> I attended a meeting with the Shrewsbury Trefoil Guild . The Guild was formed 25 years ago. I met a group of lovely ladies. The ladies held a coffee morning at Church Stretton and raised £150 which they very kindly donated to our branch. Barbara Branch, the chair, presented me with the cheque.



Our thanks to the ladies of the  
Shrewsbury Trefoil Guild.

**Joy Jones**



## What a Performance !!

**Shrewsbury Amateur Operatic Society** performed 'Fiddler on the Roof' at Theatre Severn this spring. Before each performance, they held a raffle, in aid of five local charities – including our branch of the MS Society. Cheques were presented to representatives of each charity by our very own Mary Anne – outgoing President of the Operatic Society. Jock went along to receive our cheque for £260. The other charities were Mencap, Riding for the Disabled, St. John's Ambulance, and Relate.

**Our most sincere thanks to the Operatic Society !!**



**If you would like to receive this Newsletter by email (& in full colour) please let me know: Thanks, Mim.**

## MS Week in England - Update



The MS Society held a Parliamentary reception in Westminster during MS Week, which saw a number of MPs show their support, including the Shadow Minister for Older People and Care, Liz Kendall MP. Over 3,000 of you wrote to your MP calling on them to back the campaign, and 90 MPs from across the House supported our Parliamentary petition calling for people with MS to access the right treatment at the right time, wherever they live.

For more information contact the **Communications Team** on **020 8438 0700** or email [msweek@mssociety.org.uk](mailto:msweek@mssociety.org.uk) or look at the website [www.treatmerightms.org.uk](http://www.treatmerightms.org.uk)

# mslife

## MS Life 2014 Update

Nearly 3,300 people visited **MS Life** in Manchester in April. 65 different workshops across the weekend provided a great opportunity for people to learn more about **MS research** and **symptom management**, as well as about changes to **benefits** and **services**.

Delegates who attended said: ***"I have just been diagnosed, so the workshops were an incredible help! Thank you for an amazing event, it changed my life!"*** Karine.

***"I went on my own and the people I met made me feel very comforted. I think it helps that the whole place is set up in a way that encourages people to talk and be open. MS Life was truly inspiring"*** Naomi.



## Shrewsbury Branch Income:

Snowdrop Sunday	£50.00
Subscriptions/Donations	£658.78
Dolly Hartshorn 90th Birthday	£570.00
Bridgnorth Tin Collection	£433.22
Bert Butler – Butcher	£7.44
Interest (May & June)	£26.91

**TOTAL:**

**£1,746.35**



We will be holding a **Tombola** at the **Rushworth's Magic Show** in October. We have always done very well at this event. If you have any unwanted presents, or anything that would be a suitable tombola prize, please contact Joy or Mim



**What has a head and a tail but no body?**

**A coin !**

**Change is inevitable – except from a vending machine !**

**Why don't cannibals eat clowns?**

**Because they taste funny !**



### ACROSS

1. Physics eg (abbr)
4. MGM lion
7. Takes it easy
12. Driveway sealer
13. Statute
14. Preface
15. Quarantine
17. Salivate excessively
18. Retitle
19. Poker payment
20. Matrimony
24. Region
27. New \_\_\_\_, Louisiana
30. Male sheep
31. Mothers
33. African antelope
34. Beijing natives
36. Appear
37. Not year round
40. Young lady
42. Coldest
46. Join
48. Make lively
49. Mink wrap
50. Merry
51. Star
52. Copier's need
53. Curvy letter
54. Outcome

### DOWN

1. Mix
2. Detective's assignment
3. Golf club
4. Peruvian animal
5. Diner
6. Be indebted
7. Disencumber
8. Infuriate
9. Caveman's era (2 wds)
10. Horse's gait
11. Only
16. Dalai \_\_\_\_
21. Juliet's beloved
22. Retiree's acc. (US)
23. Capone & Pacino
24. \_\_\_\_ de Triomphe
25. Stadium shout
26. Car exhaust
28. Compass point
29. Total
31. Give \_\_ \_\_ break!
32. Mule's kin
35. Snuggle
36. Slender
38. Dressed to the \_\_\_\_
39. Etching fluids
40. Have to
41. Division term
43. Comfort
44. Stupefy
45. Care for
47. Browning's always
48. Dazzle

# Shrewsbury and District MS Society Committee

Chairperson:	Peter Cornell <a href="mailto:cornellp@gmail.com">cornellp@gmail.com</a>
Secretary:	Mary-Anne Richey <a href="mailto:shrewsburymsbranch@hotmail.co.uk">shrewsburymsbranch@hotmail.co.uk</a>
Treasurer:	Jock Elliot-Smith <a href="mailto:mimandjock@gmail.com">mimandjock@gmail.com</a>
Fundraiser:	Joy Jones <a href="mailto:stickytoffee64@yahoo.com">stickytoffee64@yahoo.com</a>
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**Harold**  
07775 255697



**Tony & Jill**  
01743 850026

## Useful Contacts

### National MS Helpline

Freephone  
0808 800 8000

**Kate Watkiss** (MS  
Nurse)

07971 497902

**Next issue – Oct 2014**

### Shrewsbury Branch Helpline

**01743 718641**

24hr answerphone

**Email to MS Nurses** – for non-urgent enquiries (*not for appointment queries*) email: [info.msnurses@sath.nhs.uk](mailto:info.msnurses@sath.nhs.uk)

### Donna Moxon

(MS Nurse Administrator)  
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**All views expressed are those of individuals and do not necessarily reflect the views of the Shrewsbury Branch or the MS Society. No recommendation is being made of any products or services mentioned.**